Effectiveness of the Dennis Brown Bar in Preventing Recurrence after Ponseti Treatment for Clubfoot Deformity: A Ten Year Experience

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Colleagues & Friends,

It is my pleasure to address you in our newly formatted ACPOC NEWS. Janet G. Marshall, CPO and Robert Lipschutz, CP, took over as editors of the ACPOC NEWS from Eugene Banziger, CPO. Most of you have had the opportunity to see their first edition and I am sure all of you could appreciate the excellent job they have done. We all look forward to many more successful years and issues from this team.

As capable as our new editors are, they cannot do this all on their own. It is our society’s publication and as such, we are all responsible for its success. Our editors need your contributions, particularly in the scientific area to maintain the high quality academic content of the ACPOC NEWS. So, as members of this organization, please do show your support by submitting an article(s) for publication. Our new editors will be more than willing to offer guidance with the process.

I would like to express my thanks to outgoing editor, Eugene Banziger, CPO, who has for many years, almost single-handedly, kept ACPOC NEWS as an official publication of our organization. I hope Eugene will continue to be an active member of our organization and we will be seeing him at the annual meeting for many years to come.

Speaking of the annual meeting, I can hardly think of a more exciting venue than the Annual ACPOC Meeting 2014 location in Anaheim, California. High-quality academic content of the scientific sessions, combined with the beautiful Southern California location at Disneyland, should make it a memorable gathering for all our members and their families. Mickey Mouse cannot wait to see you all there.

Our program committee is busily organizing an exciting scientific program with a mix of paper presentations, symposia and case discussions. There should be something there for everybody. However, the overall success, will again, depend largely on the membership and the attending guests. The nature of the program format in a multidisciplinary organization such as ours, encourages and largely depends on its success by active audience participation. So leave your shyness at home and come to speak up. Questions and comments, particularly across the specialties are always welcome and encouraged. In my opinion, they contribute both to an understanding of issues across the specialties and encourage additional thinking on the subject by the presenters(s). Lastly, many thanks to all of you who have submitted their work for presentation. Without it, we would not have the quality meeting this one is shaping up to be.

See you all in Anaheim in March 2014!

Ivan Krajbich, MD
The Association of Children’s Prosthetic-Orthotic Clinics (ACPOC) provides a comprehensive resource of treatment options provided by professionals who serve children, adolescents, and young adults with various orthopaedic impairments.

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Introduction  Clubfoot deformity, also known as talipes equinovarus, is a complex three-dimensional deformity secondary to a congenital, contractual malalignment of the bones and joints of the foot and ankle. (Figure 1) Over the past two decades, treatment has evolved from surgical strategies to nonsurgical methods as described by Ponseti [1-5]. With this method of correction, the clubfoot deformity is corrected by a series of corrective casts during the newborn period. (Figure 2) In most cases, a heel cord tenotomy is performed in the clinic setting providing final correction of the deformity. The correction is maintained during the early years by an external rotation, abduction bracing protocol. (Figure 3) The post-correction bracing protocol is essential for prevention of relapse or recurrent deformity. (Figure 4) Previous studies have demonstrated poor results in patients noncompliant with the bracing protocol. Ramirez et al. in a study of 73 corrected clubfeet demonstrated a recurrence rate of 33%. Patients who were noncompliant with the bracing program were more likely to have recurrence. [6] Other authors have shown similar patterns when the bracing program was not followed.[7-10]
Currently, there are several options for external rotation, abduction braces. Ponseti utilized a pair of straight last shoes externally rotated at an angle of 70 degrees attached by a Dennis Brown bar. A custom brace was developed by Mitchell in conjunction with Ponseti which utilized custom molded shoe orthoses with leather strapping to assist in preventing foot slippage while wearing the device.[11] More recently, a dynamic orthosis allowing independent motion of the lower extremities was introduced.[12]

At our institution, the Ponseti method of clubfoot treatment was adopted in 2002. Over the past 10 years, we utilized the standard Dennis Brown bar with straight last shoes as the device of choice in our clubfoot population. A retrospective review of our experience with this device was performed to determine overall compliance with the bracing program, review outcomes related to noncompliance, and review alternative solutions.

Materials & Methods

All patients who were enrolled in the Ponseti program, completed treatment with casting and bracing, and were followed for a minimum of four years were included in the review. The current bracing protocol requires full time wear of the device for three months, followed by night time and nap-wear until age four.

Compliance was defined as successful if the patient was fully compliant with the bracing protocol until age four. Compliance was defined as unsuccessful if the patient developed recurrence prior to age four and required additional treatment, refused to wear the brace as prescribed, or wore the device on a limited basis.

Treatment outcomes were grouped based on the methods utilized to provide correction of the clubfoot deformity. The cast-corrected group was corrected by utilizing only the Ponseti method and bracing program. No other interventions were required. The minor surgery group, in addition to Ponseti casting, typically required a limited surgical event including posterior soft tissue release and/or anterior tibialis tendon transfer. The major surgery group required an extensive soft tissue procedure.

Results

One hundred thirty-two patients with 199 feet were included in the study cohort. There were 94 males and 38 females with 104 left clubfeet and 95 right clubfeet. Eighty-three per cent were Caucasian. The average age for placement of the initial casts was 44 days (range, 0-259 days). Forty-five per cent had cast treatment prior to presentation at our institution. The average follow up was 6.8 years (range, 3.1-10.6).

Success with Bracing Protocol

Of the 199 feet, 132 (66%) met criteria for successful compliance with the bracing program during the first year of treatment. During year two of the four year bracing program, 53 out of 199 were successful (27%). By year four, only 10% (20/199) were considered successfully compliant with the bracing program.

Treatment Outcomes

Of the 199 feet, 102 (51%) were successfully corrected by use of the casting and bracing protocol (cast corrected group). Of these 102 feet, 80 were fully compliant with bracing during the first year of brace treatment. By year four, only 17 of the 102 feet continued with the bracing program.

Eighty-nine out of 199 (45%) required a minor surgery, with the remaining eight feet requiring major surgery for correction. Of these 89 feet, 50 were compliant with bracing during the first year of brace treatment. During year two of bracing, only 12 of the 89 feet were fully compliant with the bracing program.

Challenges with Bracing

Families reported numerous challenges with adherence to the bracing protocol. The most common reason for lack of compliance was patient refusal to wear the brace. This was manifested as either the child refusing to don the brace or removing the brace during the middle of the night. In rare cases, other circumstances prevented compliance such as losing the brace, incorrect application by other family members.
In our current review, success with the bracing protocol following cast treatment for clubfoot deformity was limited. Only 10% of the patient cohort was fully compliant during the four years of recommended bracing. Despite the lack of compliance, treatment outcomes were favorable and comparable to prior studies with a 50% minor surgery rate and significant reduction in the need for extensive releases.

Previous authors have demonstrated that bracing is an important factor in reducing recurrence in clubfoot deformity. Thacker et al. in a review of 44 feet showed recurrent deformity in those noncompliant with bracing as measured by two clubfoot scoring systems.[7] Ramirez et al. had similar results in a cohort of 73 feet. He showed a recurrence rate of 33% with noncompliance with bracing as a significant correlation with recurrence risk.[6]

Currently, there are several brace designs available in today’s market. In a study by Hemo et al., the traditional combination of Markel shoes and Dennis Brown bar was compared with the Ponseti Mitchell brace. In his study, no differences in patient compliance or treatment outcomes were identified. [13]

The question remains, what is the relationship between recurrent deformity and noncompliance of bracing. Studies have demonstrated that lack of compliance with bracing can lead to increased risk of recurrence. Parent factors, poor fitting devices, or intolerance of bracing can lead to noncompliance with bracing and potential for recurrent deformity. Recurrence or relapsed deformity is a known entity and has been described in both cast corrected as well as surgically treated clubfoot. (Figure 2) As a clubfoot relapses, the brace may no longer capture the foot adequately leading to brace intolerance, further complicating compliance with a brace.

The bracing protocol following cast treatment for clubfoot deformity is challenging for patients, families, and practitioners. The Ponseti method is an effective method of clubfoot treatment and most likely will remain the standard of care on a worldwide basis. Improvement in brace design, foot capture, parental education and involvement will hopefully improve success with bracing and reduce recurrence during the growing years of the child.

References


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PECTUS CARINATUM: An Orthotic Approach

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Pectus carinatum (PC) is an anterior chest wall deformity associated with abnormal growth and development of the costal rib cartilages and sternum. The cartilaginous overgrowth is observed as an outward protrusion, tilt, or convexity on the anterior chest wall and often includes the sternum and associated ribs. The prominence may be either asymmetrical or symmetrical. Classification is determined by the physicality of the anterior chest wall and based on the location of prominent versus depressed areas. Accurately identifying the type of PC deformity is a crucial step in predicting orthotic outcomes.

PC Types

There have been several methods of PC classification determined and published over the last 20 years [3, 7, 10, 15]. Each classification system is based on the location of the apical or highest point of the prominence. The currently recognized classification system of PC is comprised of two categories which are differentiated by the location of the involved deformity [3]:

1. Chondrogladiolar (CG)
2. Chondromanubrial (CM)

Chondrogladiolar PC (CG) affects the mid- to lower portion of the anterior chest wall, and is the more common of the two. The prominence may include the inferior costal cartilages and portions of the gladiolus (Fig. 1). An asymmetrical version of CG often occurs with both an excavatum and carinatum component and is characterized by a unilateral protrusion with contralateral depression [16]. Chondromanubrial PC (CM), in contrast, affects the upper portion of the ribcage and is more likely to be symmetrical. It is substantially less common than CG, representing only 5% of PC cases [5]. It typically involves the superior costal cartilages, ribs 1-3, and the manubrium. The upper section of the sternum protrudes anteriorly, and the body of the sternum deviates posteriorly (Fig. 2).
Epidemiology

The incidence of PC is 1:1000 teenagers and is predominantly observed in males [2]. At this time, no definitive etiology of PC has been determined, however medical professionals have observed an increased family history of pectus deformities (25%) suggesting a genetic linkage [8]. In addition, PC has the potential to occur in association with scoliosis (21%) and other inherited connected tissue disorders such as, Marfan’s syndrome, Ehlers-Danlos syndrome, Noonan’s syndrome, and Poland’s syndrome [1]. PC may also be categorized based on etiology:

I. Post-surgical: After a sternotomy or chest trauma, the sternum does not heal in the proper position, resulting in a prominence on the anterior chest wall, albeit an uncommon occurrence. A post-surgical PC deformity will not progress or change with time.

II. Congenital: Premature fusion of segments of the sternum can occur in newborns, presenting with a rounded, prominent chest. This deformity has the potential to progress in later years.

III. Idiopathic: The most common cause and the primary focus of this article. In idiopathic PC, the deformity will typically present during active growth stages between 11-15 years of age. The deformity tends to increase in magnitude concurrently with adolescent growth spurts. Orthotic treatment appears to be most effective in halting progression and achieving skeletal correction during this period of active growth.

PC is often asymptomatic in nature, however some patients complain of significant pain at the costochondrial junction [9]. In some moderate to severe cases of PC, decreased stamina and rapid fatigue during strenuous activity has been reported [6]. Decreased exercise tolerance could potentially be related to the increased diameter and rigid expansion of the chest wall which

Flexibility

In the CG type, the deformity is significantly more flexible due to its inferior location on the anterior ribcage. The longer ribs and accompanying cartilage in the lower sections of the ribcage results in a more flexible deformity because of the mechanical advantage of distance from the sternoclavicular attachments (Fig. 3). CG PC can be effectively treated orthotically until full stature is achieved, and even later. The correction potential is greater due to the combined effect of significant cartilage flexibility and the associated mechanical advantage that persists even after full growth. Orthotic treatment has been shown to have superior results in children with CG types, due to its inherent flexibility and compliant nature [3, 7, 10].

The CM type represents a more rigid type of PC because of its superior location on the ribcage. The upper portion of the ribcage is composed of shorter, less flexible ribs reducing the overall flexibility of the CM deformity (Fig. 3). Orthotic outcomes are less optimal for patients with CM deformities due to the less yielding structure of the superior ribcage. To increase the chance of success, it is worthwhile to initiate orthotic treatment early, preferably during childhood or at the beginning of adolescence when the residual cartilage in this area is more abundant.

Figure 3: Ribcage anatomy. White section of ribs is the costal cartilage. The superior costal cartilages are shorter and the inferior cartilages are longer.
creates a challenge for the thorax to use normal chest muscles for breathing [3, 6]. As a result, accessory muscles are recruited causing respiration inefficiencies. The psychological issues of the deformity usually trump all physical symptoms for a young adult. Many PC patients complain of significant body image disturbances and often avoid showing their chest in public. PC may damage their self-image and confidence. Many of our patients initiate body building to mask the deformity. Bulking up the pectoral muscles balances the prominence and helps conceal the deformity. The psychological and social challenges of the deformity are usually the primary reasons patients seek medical attention. The resulting eagerness to initiate orthotic treatment is often helpful in assuring compliance.

**Treatment**

Surgery had been the primary mode of treatment for the past 50 years. Accepted surgical techniques include excision of the deformed cartilage with sternal osteotomy and internal fixation. Complications reported from surgery include poor long term outcomes, lengthy recovery time, and potential for recurrence [16]. In addition, restricted growth in the thoracic cavity has been noted due to the scarring and rigidity caused by the operation [14]. Consequently, surgical resection has been reserved for the most severe and complicated cases due to its invasive nature. Alternative methods of treatment were prompted as a result, and the development of a “compressive chest brace” was introduced to conservatively address adolescent PC in order to avoid such issues and complications [11]. Non-surgical methods to treat PC were first initiated and applied in the 1970’s. Plaster casts were originally used to apply pressure on the prominence to prevent further progression and promote correction. Videl et al initiated these treatments in 1977 with limited success, but provided the ingenuity behind more non-surgical treatments [18]. In 1979, the dynamic chest compressor (DCC) brace was introduced by Dr. Haje and Dr. Raymundo from Brazil, as a means to successfully treat PC with a custom orthosis [11]. They were the first team to develop a custom-fitted orthosis and document and publish its success. In 2000, Dr. Egan described radiographic proven success in treatment of PC with an orthosis [3]. His publication was followed by the first series of successful cases published by surgeons at Cincinnati Children’s Hospital demonstrating that compression bracing was safe and effective [7]. Numerous other studies have been published in the last 20 years illustrating different methodologies, outcome measures, and results [3, 7, 10, 12, 14, 15]. Overall, orthotic treatment is now widely accepted as an effective and conservative method of treatment for PC.

**Orthotic Treatment Biomechanics**

When orthotic treatment is initiated, the patient is typically in their adolescent years. During this growth period, the ribcage is capable of significant flexibility and remodeling capacity. This flexibility allows the prominent areas of the sternum and costal cartilages to be pushed back into the thorax by the anterior/posterior (A/P) forces provided by the PC orthosis. The design of a PC orthosis is based on the principles of Wolff’s Law; when healthy bone and cartilage are being loaded with a constant and increasing force, they will adapt, strengthen, and gradually remodel under pressure. The orthosis has two opposing forces, one directly over the apex of the prominence and one on the thoracic spine, directly countering and parallel to the other. Over time, this continuous force applied to the prominence arrests further anterior cartilaginous growth and gradually remodels the ribcage into a more normal, flattened shape. The PC orthosis is worn until skeletal maturity is reached; at this time is when permanent correction can be achieved, and the orthosis can be discontinued. These biomechanical principles have been validated in the design of two different PC orthoses we currently utilize for our PC orthotic treatment; one being a prefabricated design and the other being a custom design.
Prefabricated PC Orthosis

The prefabricated PC orthosis used on our patients was the Trulife Pectus Carinatum Orthosis (Trulife; Seattle, WA). It is a low-profile design with an anterior panel (3 ½” x 4 ¼”) for a posterior-directed force, a posterior panel (6” x 4 ¾”) for an anterior-directed force, and four lateral padded panels that contour around the chest (Fig. 4). The panels are made from a low density polyethylene (1/8”), which is flexible enough to easily conform around the patient’s chest, creating an intimate and concealed fit. Over time, the body heat emitted from the patient helps mold the plastic panels around the chest for further customization. The panels are covered in a foam liner (1/4” - 3/8” thickness) providing additional comfort for the patient. The panels are mounted on aluminum bars (3/4” wide) with growth extensions, making it possible to adjust the circumference and fit of the orthosis as needed. Since the Trulife PC Orthosis only comes in a “universal” size, the aluminum growth extensions promote ample adjustability during treatment and accommodate any anatomical changes that may occur during the patient’s growth years.

The anterior and posterior sections of the orthosis are connected by a tension system comprised of bilateral ratcheting buckles. There are two ratchet buckles riveted onto the anterior lateral panels that have connecting ladder straps riveted onto the posterior lateral panels. By tightening the ratchets bilaterally, A/P forces are directed on the pectus deformity. The ratchets have a quick release lever which makes it simple to loosen or remove the orthosis. The shape and design of the lateral pads provides a seamless contour around the patient’s chest creating a streamline fit that the patient can appreciate.

Custom PC Orthosis

The custom PC orthosis used on our patients was fabricated by Hanger’s National Lab, in Tempe, AZ (Fig. 5). A motion tracking laser scanner (Insignia™) was used to obtain a digital mold of the patient’s chest. In conjunction with computer-aided design (CAD) software, Insignia™ can accurately portray a cross-sectional model of the patient’s surface anatomy within a millimeter of error. The scan is then electronically sent to Hanger’s Central Design Center (CDC), where it is evaluated and modified in CAD software. A three-dimensional foam carving is produced from the final image, providing a positive mold for Hanger’s Tempe Lab to create and fabricate the PC orthosis. The
custom orthosis has an anterior and posterior panel anchored to aluminum bars that contour around the patient’s chest clearing the skin. Lateral ratchet buckles and ladder straps connect the anterior and posterior sections and provide a tightening system. All components and materials of the orthosis can be hand-selected and customized to the patient. However, if not specified, the standard materials are 5/8” poron lined kydex A/P panels, 1” x 1/8” aluminum bars, and ¾” buckles with 5/8” x 8 ½” ladder straps. Each panel is customized to the shape and size of the patient’s prominence and anatomy. If required, revision and adaptation to anatomical change during treatment can be achieved by adjusting the contours of the aluminum bars.

**Custom vs.**

**Prefabricated**

When deciding between the prefabricated and custom version, it’s crucial to perform an accurate clinical and visual evaluation of the patient’s deformity and chest anatomy. The thoracic surgeon and orthotist will collaborate to determine the design of the orthosis at their initial evaluations with the patient. A custom PC orthosis would be indicated for patients with a moderate to severe PC deformity. Patients with an atypical or asymmetric prominence, abnormal shape/size to the deformity, unconventional body shape/size may benefit from a custom designed orthosis. Additionally, young children, patients with overdeveloped muscle build (especially the pectoralis major and latissimus dorsi muscles), and females with developed breast tissue may require customized bracing. With a custom PC orthosis, it’s possible to finely contour the aluminum bars around the chest anatomy, thereby providing the appropriate clearance for a female’s breasts or an athletic male’s chest.

In contrast, the prefabricated design has a very intimate fit to the body, however does not provide the appropriate clearance for chest characteristics such as developed breasts or significant thoracic musculature. The prefabricated design is indicated for a patient with a mild, moderate, or severe PC deformity, normal muscle build, and a prominence which allows a reasonably broad contact area with the anterior pad. Overall, the prefabricated version is slightly less bulky than the custom, and in turn, usually perceived more favorably by the patient.

**Undergarment**

A Knit-Rite protective body sock is worn under the orthosis, as an interface garment to provide maximum comfort to the patient. The body sock is made from Lycra, CoolMax, and X-Static fibers which in combination helps inhibit body odor, transfer heat and moisture away from the skin, and keep the patient dry. In addition, the silver fibers embedded in the body sock produces an antimicrobial material that inhibits the growth of bacteria. The undergarment is seamless, anti-static, wrinkle free, and
stretches in all directions providing a tight fit that helps suspend the orthosis and minimize excess movement or shifting. With the continuous contact and pressure that is applied to the prominence when the orthosis is being worn, normal pressure marks can appear on the skin under the anterior and/or posterior panels. The soft interface the body sock provides reduces skin issues for the patient during orthotic treatment. The Knit-Rite body sock is an integral component of the PC orthotic protocol, addressing the common skin issues caused from heat, pressure, and hygiene.

**Clinical Evaluation**

Pectus carinatum can appear at any time during adolescence and cannot be predicted or prevented. Once the prominence shows signs of progression and has been evaluated by a physician, orthotic treatment can be initiated. The treatable age for orthotic intervention is approximately from ages 6 to 18, or until skeletal maturity is achieved and the prominence is no longer deformable. For most patients, the ideal age to initiate treatment is between 11-13 years old, close to the onset of puberty. During the clinical evaluation, a detailed medical history is obtained and a physical examination is performed. Personal background information includes: (1) demographics: sex, age, and date of birth; (2) physical characteristics: height, weight, extremity flexibility tests, sternal flexibility, and PC type; (3) medical history: associated symptoms, heart murmurs, prior surgeries, family history of pectus deformities, Marfan Syndrome, unexpected early deaths, age the defect was first noted, signs of progression, and secondary medical conditions. The physical examination includes a manual compression test, described and validated by Dr. Sydney Haje and Dr. Richard Bowen in 1992, to determine the level of residual flexibility in the chest wall. With one hand firmly on the prominence and the other hand supporting the thoracic spine, gentle manual compression is induced to verify the degree of flexibility. Haje states that if partial or complete reduction is observed, the deformity is considered “flexible”. He then categorized the degree of flexibility by dividing it into two subgroups, patients with a “flexible” or a “rigid” protrusion. Determining the flexibility of the chest wall prior to treatment is helpful in predicting clinical outcomes. Clinical photographs and anthropometric measurements are taken at each appointment to track physical changes and create a chronological, visual and quantitative record of the patient’s progress for objective comparison. Clinical photographs are taken with a digital camera and hard copies stored in the patient’s file for analysis. Multiple angles of the patient’s chest are recorded including: (1) anterior view; (2) posterior view; (3) bilateral lateral views; (4) bilateral anterolateral views; (5) supine view. The anthropometric measurements are obtained by a skilled, certified orthotist using a sliding mediolateral (M/L) gauge and a flexible tape measure. The measurements are taken up against the skin, with the patient’s shirt removed, for increased accuracy. A total of 3 measurements are recorded, which include circumference, M/L diameter, and an A/P diameter at the apex of the prominence. Measurements are taken consistently throughout the course of treatment to quantify correction and clarify the relationship between growth parameters and the response to the orthosis. A tracking form is utilized to follow progress during the treatment process (Tab. 1).

**Fit and Follow-Up**

The PC orthosis is fit by a certified orthotist and the patient is educated on adequate tightening of the ratchets to systematically increase pressure throughout treatment. A break-in schedule is recommended initially, in order for the patient to gradually adapt to the pressures of the orthosis. A typical break-in schedule is as follows:

Day 1: (1 hour): Wear for 30 min, then another 30 minutes later in the day.

Day 2: (2 hours): Wear for 1 hour, then another hour later in the day.

Day 3: (4 hours): Wear for 2 hours, then
another 2 hours later in the day.

**Day 4:** (12 hours): Wear for 4 hours during the day, and then to bed (8 hours).

**Day 5:** (14 hours): Wear for 6 hours during the day, and then to bed (8 hours).

**Day 6:** (16 hours +): Wear for 8+ hours during the day, and then to bed.

Full-time hours range between 16-20 hours per day; with nighttime hours satisfying part of the required time. The orthosis is not allowed to be worn during any strenuous, physical activities, or taken into the shower/bath. Typically, the orthosis is worn full-time for the first 3-12 months or until significant correction has occurred. Some of our patients that choose to wear the orthosis longer (18+ hours/day), had a quicker response to treatment, typically with significant correction in the first 3-6 months. Once full correction has occurred, wear-time can be reduced to 12-14 hours per day until at least 3 months of maintained correction is observed. After 3 months, wear-time can be decreased to just nighttime use (8 hours/day) until the end of treatment; this is the “maintenance” period. The patient must be watchful, as recurrence may occur when wearing the orthosis for less than 14 hours per day. The patient follows-up with their referring doctor and orthotist frequently within the first couple of months, in order to closely monitor and track the rapid changes and improvement that commonly occur within the first 3 months of compliant treatment [4, 7]. Follow-up occurs with the orthotist 4 weeks post-fit, then again in 4-6 weeks, and then every 3 months to ensure proper fit of the orthosis, address any problems or concerns with protocol, monitor compliance, and track physical changes. The patient also needs to have regular follow-ups with their doctor. Commonly, the patient will follow-up with their doctor 2 weeks post-fit, then again in 6 weeks, and then every 6 months. Orthotic treatment duration is on average for 24 months, or until linear growth ceases [7, 17].

**Conclusion**

Utilizing an orthosis to treat PC has had gradual recognition in the last 10 years, and in recent years, many doctors are considering it as a first-line treatment for PC [12]. The orthosis has proven to be a safe and effective way to provide favorable outcomes with the possibility to avoid surgical options or having to live with the deformity. In addition, the success of the orthosis increases if the following factors are present; chondrogladiolar PC type, ribcage flexibility, early intervention, and compliancy. However, it is patient compliance that is the single most important factor in achieving optimal results with the orthosis. If adequate, full-time hours are not applied during treatment, the deformity has the opportunity to progress and orthotic treatment becomes ineffective. Therefore, it is crucial for the patient and family to understand the importance of compliance in order for orthotic treatment to be productive.

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**TABLE 1: Pectus Carinatum Tracking Form**

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<th>Patient Name:</th>
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I was 25 years old by the time I truly understood what proximal femoral focal deficiency (PFFD) was.

It was 2002, two years into my marriage, when I developed a sudden and severe case of ‘baby fever’. My husband and I didn’t worry about having enough money, or whether our careers were in the ‘right’ place at the time. There was, however, one lingering thought in the back of my mind: could I carry a baby safely, in my body or even in my arms?

Birth Story
As a child, the details surrounding my birth and anatomy seemed like part of an urban legend. One of my favorite bedtime stories was my birth story. I would beg to hear it and my mom would recite it, like I had never heard it before, as I curled up in her lap, captivated.

My mom knew something wasn’t right when she was pregnant with me because I didn’t kick as much as her other children. She shared her concerns with her doctor, but he dismissed her. When I was born, the doctors whisked me away and hurried out of her hospital room saying, “There’s something wrong with her.” When they finally brought me back, my mom scoffed at their panic. “That’s all?” she asked. She thought I was perfect, as-is, and couldn’t understand what all the fuss was about.

That is the version of my birth story that I heard growing up. As an adult, I asked my parents to finally talk more candidly about this experience. It turns out that they were actually confused, worried, sad, guilty, and isolated. But, they never wanted me or my siblings to know.

There was no formal diagnosis provided to my parents in 1977. All they knew was that my left femur was very short, my right leg was only a thigh that stuck out to the side and ended with a misshaped foot, and my hips had limited range of motion. Before I was even old enough to sit up, the doctors said I would never walk. My parents immediately put their house up for sale and contracted the construction of a completely wheelchair accessible home. Being a typical middle class family, this must have been a financial and logistical nightmare. I have never asked my brother and sister, who were 10 and 8 at the time of my birth, how they felt about all of this back then. I know they had to leave their neighborhood friends and change schools. They only thing I know, perhaps part of the urban legend, was that they thought I was adorable and argued over who got the privilege of changing my diaper.

Nothing to Hide
My family taught me not to hide my limb difference. My mom kept me in diapers and shorts the majority of the time and answered questions from curious strangers with shameless grace. As a young child, I absorbed these interactions and appropriated
the same attitude as soon as I could answer the questions for myself. To this day, I treat stares and questions from strangers as educational opportunities—rare chances to connect in a disconnected society. My own children sometimes answer for me. It is so fulfilling to hear my children say, unprompted, “She was born like that. It’s cool and she can do everything your mom can do.”

I received my first prosthesis when I was approximately 12 months old. It was crude and designed to only allow me to stand with full assistance. With this device as my only prosthetic option, it seemed like the doctors’ predictions of me being wheelchair bound would be accurate. It was a neighbor, a Shriner, who suggested that my parents should seek another professional opinion.

New Hope To the team at the Greenville, South Carolina Shriners hospital, the solution to my situation was very clear: amputate the tiny right foot, straighten the right thigh so its position is anatomically correct, and fabricate a properly designed prosthetic limb.

The possibility of me walking independently helped my parents overcome their fear of the surgery. I was 18 months old when I had the amputation. At first my mom stayed with me at the hospital, but she eventually had to return to our home in Orlando, Florida to look after my siblings. I think about that now, as a mother myself, and cannot imagine how gut wrenching that decision must have been for her. But the nurses were right—I was fine there. I remember the hospital bed bars and the nurses, who always smiled. The doctors showered me with attention. I still have the stuffed horse my mom brought to me the first time she came back to the hospital to visit. I named my new little leg ‘Toe-Toe’. I still call it that today, as does my husband and my daughters.

Traveling from Orlando to Greenville for each prosthetic fitting appointment was quite an adventure. I looked forward to these trips like most kids look forward to Christmas. I relished these times when it was just me and my mom, staying at hotels, eating out, and chumming with the medical staff, who treated me like a celebrity. I don’t know if medical professionals truly realize the impact that this treatment has on a patient: to feel special, to feel like the medical team is part of their family. When the Tampa Shriners Hospital opened, we were excited, but sad to say goodbye to our magical trips and those thrilling, rickety single engine planes.

It did not take long for the Tampa Shriners Hospital team to feel like family too.

Growing Up As I grew, so did my closet collection of old legs (I kept my favorites). They are tangible memories, each one slighter taller that the last, with more technological perks. In addition to technological advances, their aesthetics changed along with my preferences. As a young kid, I couldn’t care less what they looked like. By middle school, we ditched the exoskeletal design and transitioned to endoskeletons with inconspicuous one-piece foam covers. That’s around the same time that I insisted on contact lenses rather than my coke-bottom glasses. By my second year of high school, I was too alternative, artsy, and rebellious to be an amputee incognito. That’s when I tore off my cosmetic foam cover and started to enjoy the extra attention. But, I kept the contact lenses.

I feel fortunate to honestly say that I can only remember a few moments in my teen years when I wondered if boys did not ‘like’ me because of my leg. That kind of thinking seems inevitable at some point, considering the level of shallow criticism young people impose on themselves and others. But these thoughts were fleeting and I chose to see my limb difference as a filter for dumb boys who were too bland to appreciate unique people.

I met my husband at a party in college. At the time, I wasn’t wearing a prosthesis and exclusively used forearm crutches. His ‘come on’ line was, “Girl, you’ve got some strong arms.” I was hooked. He never had to ‘look beyond’ my limb difference, or love me ‘despite

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it’. My husband loves my limb difference because it was part of who I am.

Baby Time Back to 2002 and our family planning: I knew my pelvis and hips possessed some fundamental design anomalies. The last thing I wanted was a lost pregnancy. That is when I began doing some overdue research. Unlike my parents, who did not have the luxury of internet in 1977, my search for information required minimal effort. It did not take long for images of children with short femurs to appear on the monitor. I was speechless. These kids looked just like me. I requested my medical records and x-rays from the Shriners Hospital—the physician narratives and x-rays were like a strange journal of my life that someone else had kept for me.

I collected all of my information and made an appointment with an OB office near my house. The nurse literally said, “Oh, you poor thing,” and the doctor said my case was too complicated. I called upon all the encouragement I received growing up, got off the examination table, collected my belongings, and walked out the door with all the dignity in the world. By the time I got into my car, I felt deflated and hopeless.

I threw a little pity party for myself as I drove and then called a high risk OB to set up an evaluation. Life had taught me to keep trying. The high risk OB I found did some research on PFFD, even though there was very little written about PFFD and pregnancy at the time, looked at my x-rays and told me that he couldn’t treat me. I wasn’t high risk enough. He said, “I think you’ll be just fine.” This thoughtful, thorough man handed me my x-rays and referred me to a regular OB group. Today, I am the proud mother of two children, both delivered vaginally, without complications.

Looking Back to See Ahead
I would like to believe that I was born with an innate inner strength and spirit of perseverance. In reality, my ability to embrace my body was greatly influenced by the people around me: a supportive family that defined beauty in open and relative terms, encouraging teachers that nourished my talents, nonjudgmental neighbors and friends, and a loving medical team. I never allowed my limb deficiency to define my life, but I value it, like I value my gender, sexuality, and ethnic background.

Wanting to ‘pay it forward’ is a major reason why I eventually joined a private prosthetic facility, Westcoast Brace & Limb, as a support staff member. I wanted to help other patients feel valued and encouraged. I have a feeling that’s why there are so many amputees that work in the prosthetic industry. As patient/professionals, we have a unique perspective and a heartfelt desire to see other people succeed, just like we did. As an adult prosthetic user, my prosthetic designs have continued to evolve with microprocessor technology, new fitting methods, and even, my favorite, a foot for high heel shoes.

My new goal is to finally become a published writer and illustrator, with a soft spot for children’s stories about disability. In my stories and illustrations, I try to encapsulate a lifetime of lessons from my family, friends, and medical professionals. These lessons have proven to me that the human spirit can transcend bodily limitations and take us to surprising places. I think it’s important to pass that lesson on to everyone: children, family, friends, and even strangers on the street.
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Children’s Powered Prostheses

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ULTRAFLEX SYSTEMS Thanks the O&P Profession: Celebrating 200,000 Patients Milestone

POTTSTOWN, PA, USA – September 18, 2013 - Ultraflex is strongly committed to the O&P profession and is celebrating its 23 years of partnership at this year’s AOPA 2013 O&P World Congress. Ultraflex technology is and has always been available only through certified orthotists. The result of this policy and partnership is helping over 200,000 patients. Ultraflex will publicly acknowledge this significant patient milestone and also reaffirm its commitment to the profession and evidence-based practice at an evening celebration on September 18, 2013 in Orlando, Florida, USA.

“It is a privilege to support the O&P profession’s dedication to patient success and to endeavor to provide orthotists with the scientific evidence, case studies, and education needed to provide patient care with confidence,” said Mark DeHarde, President and Founder of Ultraflex Systems, Inc. Ultraflex’s history pioneering dynamic stimulus and Adjustable Dynamic Response™ technology is backed by years of research and continues today with ongoing independent comparative effectiveness studies. “The first prospective comparative effectiveness evidence
showing the superiority of Ultraflex dynamic stimulus bracing over static bracing in terms of efficacy, reduction of contracture, reduction of spasticity, and compliance represents the most compelling research to date to substantiate what has long existed in practice,” DeHarde further stated.

In conjunction with its orthotist partners, Ultraflex conducts clinical education with live patient labs in major clinical communities across the US specializing in neuro-rehabilitation. Ultraflex’s curriculums are approved by governing bodies for orthotist and therapist CEUs. Since 2011, more than 1500 practitioners consisting of physicians, physical therapists, occupational therapists, and orthotists specializing in pediatric and adult neuro-rehab attended Ultraflex courses and followed our patient lab participants’ progress. Ultraflex is grateful for this collaboration that provides ongoing feedback for further enhancements to patient solutions and further investment in collaborative research studies.

In 2013, to meet the needs of the growing community of Ultraflex patients and to better support orthotist partners, Ultraflex opened a state-of-the-art 9,000 square feet CFAB facility. Ultraflex CFAB specializes in challenging upper and lower extremity designs for patients with chronic neurological conditions. The facility’s design supports advanced lean manufacturing methods resulting in quality and consistency of design and industry-leading turnaround times.

About Ultraflex Systems

Ultraflex is committed to supporting our patient communities, their caregivers, and the healthcare professionals involved in their care in the mutual goal of improving patient quality of life. Ultraflex’s areas of specialty include therapeutic bracing with precise dynamic stimulus and proper posturing for challenging neurological presentations, functional bracing with Adjustable Dynamic Response™ for managing gait dysfunction, post-surgical protection and structural LOM bracing for complex orthopedic rehabilitation. Ultraflex FDA Class I braces are available only through a physician’s prescription and are fitted by certified orthotists. Ultraflex’s commitment to the O&P professional community includes participation and support of the National Association for the Advancement of Orthotics and Prosthetics (NAAOP), the Orthotic and Prosthetic Alliance, and Orthotic and Prosthetic Education and Research Foundation (OPERF).
In November ACPOC’s elected Board of Directors met in Rosemont, Illinois at the AAOS board room with Ivan Krajbich MD presiding. Highlights of the meeting include discussion and approval of the 2014 budget, led by Jorge Fabregas MD the secretary/treasurer. It is always a challenge to maintain membership, financially successful annual meetings, and advertising/sponsorships from our exhibitors. Strategic planning and discussion ensued to secure a viable plan to sustain our association. It was voted to have a marginal increase in membership dues, since they have remained the same for a number of years, raise the registration fees for the annual meeting slightly, but maintain the same exhibitors fees and advertisers fees for the next year. The funds from OREF donations will be used to offset the cost of guest speakers for the annual meeting. Our financial status for ACPOC is stable at this time.

Review of the 2014 annual meeting in Anaheim, California shows promise of being outstanding with a packed two and one half days of presentations. Rather than having the Friday night banquet, which was a higher cost than could be justified, an alternate plan was chosen. Smaller groups can sign up at the meeting for their choice of several local restaurants, and then be organized into larger groups with reservations for that restaurant. The hope is to still have socializing within the membership at a more affordable cost and a bigger venue of options. The 2015 Annual Meeting will be held in Clearwater, Florida Hilton Beach Hotel in mid-May. Further research has begun for choosing locations for the 2016 and 2017.

The slate of nominations for 2014 Board of Directors thus far include: Vice President – Jorge Fabregas MD; Secretary-Treasurer – Hank White DPT; Member at Large (2 positions) -- Anna Cuomo MD; Todd De Wees CPO; Fallon Stewart ARNP; Benjamin Walker CPO.

It was voted to designate leadership for ACPOC News with Janet Marshall CPO as Managing Editor, and Robert Lipschutz CP as Co-Editor to carry on the production of the newsletter. There was extensive discussion on how to modernize the website and make it more “user friendly”. Ideas on advertising on the website are also under investigation with a committee in place to work on this project.

The board will meet again at the annual meeting in Anaheim, but will continually be working through communications via emails to make it great.
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➢ MORNING
  Occupational Therapy for the Child with an
  Upper Extremity Prosthesis Workshop
  (Separate Registration Required)

➢ AFTERNOON
  Technical Workshops:
    Allard
    Ultraflex
    Fillauer

➢ EVENING
  Venders Reception

THURSDAY  March 6

➢ MORNING
  Welcome

  Session I – Lower Limb Orthotics & Motion
  Analysis (Four Scientific Studies)

  Symposium I – Serial Casting for Long-Term
  Correction of Equines Deformities

  Session II – Lower Limb Orthotics (One
  Scientific Study & Three Case Studies)

➢ AFTERNOON
  Presidential Guest Speaker: Michael Sussman, MD
  Physician Guided Clinical Forum Workshop

  Session III – Surgical Enhancement
  (Three Scientific Studies)
FRIDAY

MORNING

Session IV – Spina Bifida
(One Case Study & Two Scientific Studies)

Symposium II – Reciprocating Gait Orthosis

Session V - Spine (One Case Study, One Creative Solution, & One Scientific Study)

Session VI – Trunk (Two Scientific Studies)

Session VII – Multi-Limb Involvement Prosthetics
(Two Case Studies & One Scientific Study)

AFTERNOON

Business Meeting Lunch for ACPOC Members Only

Hector Kay Lecture – Lori Karol, MD – Spinal Bracing

Session VIII - Function and Quality of Life
(Three Studies)

Session IX – Prosthetics – General
(Four Studies)

Symposium III – Using Sport and Physical Activity to Improve Holistic Wellness and Teach Life Skills

SATURDAY

MORNING

Session X – Upper Limb (Four Scientific Studies)

Session XI – Motion Analysis (Four Scientific Studies)

Symposium IV - Neurofibromatosis: Surgical, Orthotic, & Rehabilitation Management in Children

Session XII – Lower Limb (Four Studies)

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- OTH De Hoogstraat - Utrecht, Holland
- Pro Walk GmbH - Egelsbach, Germany
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- Vitality in Motion - South Wales, United Kingdom
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